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**STATEMENT OF SENATOR EDWARD M. KENNEDY ON GENETIC INFORMATION
NONDISCRIMINATION ACT**

***(AS PREPARED FOR DELIVERY AT HEALTH, EDUCATION, LABOR, PENSIONS
COMMITTEE EXECUTIVE SESSION)***

It's a privilege to place before the committee for consideration today the Genetic Information Nondiscrimination Act. It's an honor to join Senator Snowe, Senator Enzi, Senator Dodd, Senator Harkin, Senator Gregg, and other members of our committee in support of this needed legislation.

I especially commend Senator Snowe for her leadership in this effort to establish protections for the public against genetic discrimination. It's now over a decade since Senator Snowe first introduced legislation on the issue. It passed the Senate 98-0 in the last Congress, and I'm very hopeful we can work with our colleagues in the House and enact it into law, so that our people will finally have the protections they need against the misuse of genetic information.

In this century of the life sciences, much of what we learn through biomedical research is being translated into new treatments and cures, and nowhere is the explosion of scientific progress more apparent than in the field of genetics. Four years after the remarkable achievement of discovering the sequence of the human genome, clinical testing is now possible for over a thousand genetic diseases. It's led to rapid growth in the field of personalized medicine, in which patients' treatment and care is individualized according to their genetic make-up.

In the absence of federal protections, however, patients fear that undergoing genetic tests may lead to disqualification from future insurance coverage, or that an employer will fire them or deny a promotion based on the results of a genetic test. The consequence is that many Americans are choosing not to be tested, and are declining to participate in clinical trials so important for the development of new treatments.

Discrimination based on genetics is just as wrong as discrimination based on race or gender. Our bill provides specific protections for citizens against genetic discrimination. It prohibits health insurers from picking and choosing their customers based on genetics. Employers cannot fire or refuse to hire persons because of their genetic characteristics. It enables Americans to benefit from better health care through the use of genetic information, without the fear that it will be misused against them.

It is difficult to imagine information more personal or more private than a person's genetic makeup. It should not be shared by insurers or employers, or be used in making

decisions about health coverage or a job. It should only be used by patients and their doctors to make the best diagnostic and treatment decisions they can.

In the near future, genetic tests will become even cheaper and more widely available. If we don't ban discrimination now, it may soon be routine for employers to use genetic tests to deny jobs to employees, based on their risk for disease.

If Congress enacts clear protections against genetic discrimination in employment and health insurance, all Americans will be able to enjoy the benefits of genetic research, free from the fear that their personal genetic information will be misused. If Congress fails to make sure that genetic information is used only for legitimate purposes, we may well squander the vast potential of genetic research to improve the nation's health.

The bill that we are considering today has been unanimously approved by the full Senate in the past two Congresses. We passed it 95-0 in the 108th Congress, and 98-0 in the 109th Congress. It had over 240 co-sponsors in the House in both Congresses, but the leadership refused to bring it to a vote.

As President Bush himself has said, "Genetic information should be an opportunity to prevent and treat disease, not an excuse for discrimination. Just as our nation addressed discrimination based on race, we must now prevent discrimination based on genetic information."

We're closer than ever to enactment. I urge the Committee to approve the bill, and this time, I think we'll finally see it become law.